



**Arizona Department of Health Services  
Office for Children with Special Health Care Needs  
Integrated Services Grant**



**Parent Action Council  
February 23, 2006  
Conference Call Meeting Minutes**

In June 2005, the Arizona Department of Health Services, Office for Children with Special Health Care Needs was awarded a three year grant entitled, "Integrated Services for Children with Special Health Care Needs, Priority #5: The President's New Freedom Initiative: State Implementation Grants for Integrated Community Systems for Children with Special Health Care Needs." The Grant was awarded by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB). The Grant proposes the creation of the newly formed Arizona Integrated Task Force and eight (8) committees comprised of stakeholders from governmental and state agencies, local, and community level providers, parents, children and youth with special health care needs (CYSHCN), and their families. The Parent Action Council has been formed for this purpose and held its inaugural meeting on January 12, 2006 at the Arizona Department of Health Services in Phoenix.

**Parent Action**

**Council Purpose:**

Provide a single informational resource about all activities involving parents throughout the state, and to facilitate cross training, and mentoring of all parents. The Council will review local activities and make recommendations to the Task Force.

**Facilitator:**

Marta Urbina  
Health Program Manager III  
AZ Dept. of Health Services-Office for Children with Special Health Care Needs

**Principle Investigator:**

Jacquilyn Kay Cox, PhD  
Section Manager-Data, Planning and Evaluation  
Principal Investigator - Integrated Services Grant  
AZ Dept. of Health Services - Office of Children with Special Health Care Needs

**Attendees:**

Trini Ferra - Parent Leader  
Linda Hamman - AZ Department of Health Services/OCSHCN  
Gretchen N. Jacobs - Greenberg Traurig, LLP

Denise Jones - Parent Leader

Linda B. Strayer - Tucson Community A.C.T.I.O.N. Team

Marta Urbina - AZ Department of Health Services/OCSHCN

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
<b>Welcome &amp; Introductions</b>	Marta Urbina, ADHS- OCSHCN  Council Members	Everyone introduced themselves again after the conference call operator conducted roll call. A number of the Council members indicated that they were not able to participate on this call but wanted to be kept informed through the conference call meeting minutes.  We all agreed to be mindful and patient of our new learnings related to this grant. We all need to be able to continue asking and further clarifying, “what is my role” and “what do we need to accomplish as a result of our participation on this grant?”	
<b>Review of Action Items from Jan. 12, 2006 meeting</b>	Marta Urbina	Our conference call agenda was developed as a result of a number of action items identified at the January 12 <sup>th</sup> meeting. We will continue using the Parent Action Council “Committee Action Planning” tool to guide our work.	
<b>Increasing the number and diversity of the Parent Action Council</b>	Council Members	A draft family profile will be developed to help us increase the number and diversity of the Parent Action Council. The members discussed the importance of reflecting as much diversity as possible so that the Council would be well represented by: --geographic area --age of daughter/son, individual with special health care needs --disability or special health care need --agency(ies) utilized by child/youth/adult with special health care needs --language(s) spoken	Develop draft profile for review and approval
<b>Increase our communication</b>	Council Members	As a new developing Parent Action Council we want to maximize our time together. Everyone agreed to have their personal information shared with one another. This Council is	Contact information released for public use such as the website, will include only the member names,

		<p>unique in that their contact information reflects their private residences and all want to have their personal information protected.</p> <p>Everyone agreed that meeting face to face on a quarterly basis with one hour conference calls in the in between months would work for all. In order to continue working on the goals and outcomes of the grant, the Council members will also meet telephonically for a one hour conference calls when not meeting face to face.</p> <p>The Parent Action Council members do not all have access to electronic mail so we will need to be attentive to the needs of members receiving information using regular mail and/or fax.</p> <p>Not all the Council members have a long distance telephone service. The Children's Information Center has a toll free number, 1-800-232-1676 that can be utilized to contact the Office for Children with Special Health Care Needs' staff. Simply ask for staff by name and/or staff telephone number.</p>	<p>the community they represent and a telephone number.</p> <p>Face to face meetings scheduled for April 13, July 13 and October 12, 2006.</p> <p>One hour conference calls are scheduled for the 3<sup>rd</sup> Thursday of each month from 10 – 11 a.m. for 2006 (March 16, May 18, June 15, August 17, September 21, November 16, December 21)</p> <p>Facilitator will arrange calls with the state conference call operator.</p>
<b>Training</b>	Council Members	<p>The Parent Action Council is very much interested in ensuring that families have access to training especially when there are costs attached. These can include training or conference registration but also the expenses families incur when childcare and/or respite is needed. The need for transportation was also discussed. Parent Community Development Leaders shared how training is delivered through their local Community Action Teams.</p>	<p>Parent Action Council members felt it is important to collaborate and/or coordinate with the Education Committee on this issue.</p>

		<p>Also discussed the need to increase training opportunities for leadership development. The Arizona Department of Health Services/Office for Children with Special Health Care Needs Learning Management System was identified as one key resource to families. The Parent and Youth Leadership Curriculum will be web based so families can simply access this training on their computers. However, not all families have access to technology. When discussing remote, isolated communities within our state, a number of resources for accessing technology were identified within communities that included tribal offices, schools and some community centers. Travel needs and transportation were sited as barriers to this resource. Lack of technology and how to use it can also be a barrier to accessing this information. Perhaps VHS or DVD training formats can also be developed.</p> <p>One of our grant outcomes relates to Task I, Outcome/Performance Measure II, “family members work with their professional partners to provide training (pre-service, in-service and professional development to MCH/CSHCN staff and providers”. The Parent Action Council clarified that this can be general training that is parent driven or organized, that it is more than 1:1. If evaluations are used, identify the means of getting the information.</p>	<p>Parent Action Council will gather resources that support parents financially to participate in training. Develop document to take forward to the Task Force.</p> <p>Develop a draft training/education tracking form.</p>
<b>Current tasks of grant committees</b>	Council Members	<p>Everyone felt it was important to be well informed about what the other committees or councils are working on as their goals and outcomes.</p> <p>Could an at-a-glance document be developed and disseminated and/or posted on the website, <a href="http://www.azis.gov">www.azis.gov</a> ?</p>	Move this forward as a recommendation to the Task Force.
<b>Inquiries made of the grant</b>	Denise Jones  Council	<p>Denise sent an e-mail to the Office for Children with Special Health Care Needs questions/suggestions based on her review of the grant.</p> <p>Not all of the Council members have had an opportunity to</p>	Denise requested that Marta send it

	Members	review Denise's questions, so discussed the potential of sending it out to everyone for review. This Parent Action Council process provides a great opportunity to collectively make decision based on individual contributions. We want to ensure that everyone is informed about their interactions with one another and/or within the Integrated Services Grant staff.	to all
<b>Next Conference Call Meeting</b>		<b>March 16, 2006 10 – 11 a.m. Parent Action Council members will be contacted by the conference call operator.</b>	Agenda items to include draft tracking/education form, response to inquiries made of the grant, develop resource that support parents financially to participate in training, at-a-glance current tasks of committees, presentation on the Community Development approach and philosophy at April's meeting.